

ShowCase

Love Your Mouth

Topic:

Cancer

Organisation:

Newcastle-Upon-Tyne University

Location:

Newcastle; Gateshead (North East)

Dates:

2006 to 2009

Budget:

£47,600

Website:

www.openuptomouthcancer.org/aboutthecampaign/local_activities/northeastpilot

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Overview

Love Your Mouth was a pilot initiative funded by Cancer Research UK to promote early detection of oral cancer in the North East of England.

The aims of the intervention were to create a user-friendly service in Gateshead and Newcastle where people at risk from oral cancer could have their mouth examined by a competent clinician.

Love Your Mouth developed a voucher system, which enabled holders to receive a free soft tissue mouth check at a participating dental practice. Over the 2 phases of the intervention, over 3,000 Love Your Mouth vouchers were printed and distributed in booklet form to pharmacies, smoking cessation services, health trainers, NHS walk-in centres and medical practices in the Newcastle and Gateshead area.

Results (Phases One and Two):

- 485 'assessment of risk' vouchers distributed to at-risk individuals
- 101 dental appointments attended for a soft tissue mouth check
- Five voucher holders referred to specialist oral surgeons by the dentist
- One person kept under review as a possible cancer sufferer



Mouth cancer kills one person every five hours in the UK. In 2006 doctors diagnosed 5,325 new cases of mouth cancer in the UK and 1,850 died from the disease in 2007. Survival rates are low due to late presentation of symptoms. If the early signs of mouth cancer are diagnosed early enough, survival rates are positive.

The disease is more common in people who are socially deprived, who live in the north of the UK, and who smoke tobacco and drink alcohol. In the UK oral cancer is more common in men than in women; however, the sex ratio has decreased rapidly from around 5:1 50 years ago to less than 2:1 today.

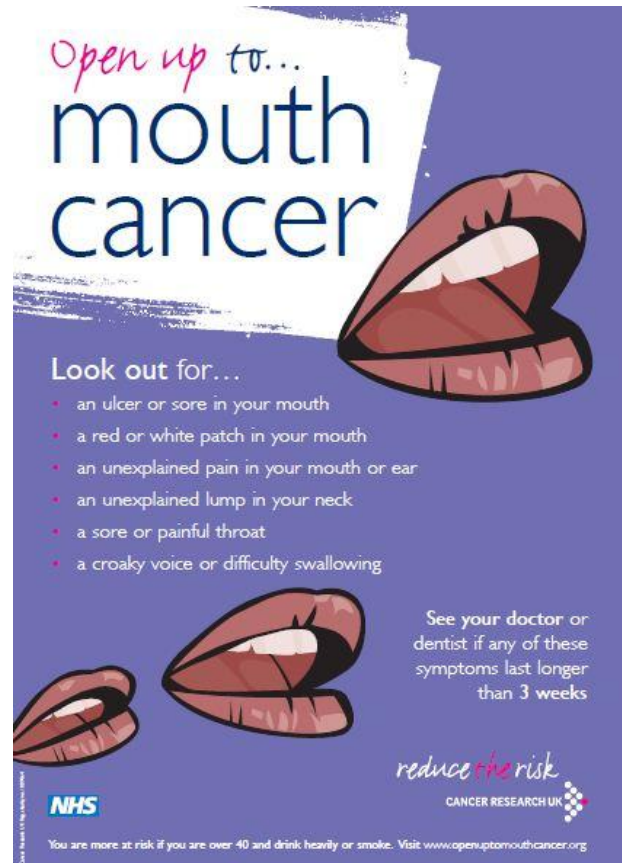
Previous campaigns to raise awareness about mouth cancer have either failed to engage the most at-risk target population, or have over-stimulated response and flooded the referral route with the 'worried well'. In addition, research shows that doctors and pharmacists are more likely to be approached for information than dentists and that there is widespread reluctance to see a dentist in connection with oral cancer.



In 2005, Cancer Research UK launched a national campaign, 'Open Up to Mouth Cancer', which had the following objectives:

- Increase knowledge of the early signs of mouth cancer
- Increase awareness of actions that can be taken to detect the disease early

- Positively influence attitudes towards early presentation
- Raise awareness of methods for effective prevention



Open Up to Mouth Cancer was targeted at groups of people most at risk of developing mouth cancer. The campaign:

- Provided information about mouth cancer through the Cancer Research UK website, leaflets and posters
- Worked with the media to help put awareness of the signs and symptoms of mouth cancer and how to detect it earlier on the national agenda
- Worked with health professionals to promote earlier diagnosis of mouth cancer
- Supported health professionals working on mouth cancer and in related areas at a local level
- Funded mouth cancer research and trials looking at the best ways to encourage the

prevention and early detection of mouth cancer

The Open Up to Mouth Cancer campaign funded three local pilot projects as part of the Oral Cancer Case-finding Intervention Project (OCCIP), specially designed for higher risk communities in the UK:

1. Tower Hamlets – Raised awareness of mouth cancer amongst the Bangladeshi community
2. Newham – Worked with the Bangladeshi and Pakistani communities to help raise awareness of prevention and early detection of mouth cancer
3. Newcastle and Gateshead – Focused on the early detection of mouth cancer among people aged over 40 who smoke and drink heavily

This case study focuses on the North East England (Newcastle and Gateshead) mouth cancer pilot, 'Love Your Mouth'. The Love Your Mouth project was informed by policy recommendations outlined in the 2005 *Choosing better oral health: An oral health plan for England*.



Behavioural goals

The overall aim of the Love Your Mouth project was to:

- Engage and motivate those most at risk from oral cancer to seek early screening and diagnosis or to eliminate them from follow-up, in a uniquely designed screening/referral intervention based on social marketing techniques

Specific objectives were to:

- Engage local service providers in the North East to establish a satisfactory final common pathway to diagnose potential oral cancer cases
- Identify and prime screening services and professionals who could capture, screen and direct possible cases of oral cancer, above and beyond the usual spontaneous diagnostic level, into the final common pathway
- Identify at-risk target populations within the North East
- Develop and roll out effective interventions with the target population and health professionals



Segmentation

Primary audience (at-risk individuals)

Oral cancer is more common amongst people who are socially deprived, who live in the north of the UK, and who smoke tobacco and drink alcohol. It is also more common in men than in women. However, these individuals usually have low awareness of the cancer's signs, symptoms and risk factors, so present too late for successful treatment.

They are also unlikely to access regular primary dental care (one common way oral cancer is identified early). Love Your Mouth targeted individuals based on the following risk assessment criteria:

- Two years or more since the last visit to a dentist (regular attendees automatically)

receive a soft tissue mouth check as part of their check-up)

- Adults aged over 40 years
- Smoking or using tobacco in other forms (the equivalent of smoking 15 cigarettes or more a day)
- Drinking above the Department of Health's (DH's) recommended units of alcohol per week

Secondary audience (dental staff)

In order to support the referral process, a service was needed that was user-friendly and likely to encourage users to feel comfortable once they accessed the clinical screening service in their dental practices. Subsequently dental staff would play a key role.

Tertiary audience (other healthcare professionals)

The 'sales force' was identified in primary care as those professionals who the target group were likely to be in contact with, such as pharmacists, smoking cessation teams and general medical practices.

Primary research

In-depth stakeholder interviews with health promotion professionals revealed frustration around the existing service, including screening facilities often being in specialist clinics with minimal outreach activity, little being done by existing services to become user-centred and no commitment to developing communication strategies with target populations at risk from oral cancer.

Focus groups were conducted with male and female members of the primary target audience.

Insights

- Health and family were the most important things in the lives of participants. Most of them were parents and grandparents, working full or part time, who felt that a poor state of health would jeopardise their family life and financial security

- Most smoked and drank, acknowledging that their state of health was not as good as it could be
- On spontaneous recall, of all areas of the body affected by cancer, oral cancer featured low on the list
- There was awareness that oral cancer affects the soft tissue of the mouth, but a lack of knowledge of its actual symptoms and means of prevention
- Some participants associated oral cancer with smoking, but most were not aware of its links with alcohol consumption

Barriers

- Existing health services were seen as unfriendly, unwelcoming and frightening
- Perceptions that such services were not for them
- Fear of the dentist – that it would involve expense and discomfort
- Low levels of self-esteem, especially in relation to health, and so shunned opportunities to engage with health professionals – Many ignored attempts by health professionals to engage with them
- Many of those who were at risk were not aware of their own risk status

Competition

- Target audience's traditional hostility towards health communications
- A range of other publicity campaigns competing for the target audience's attention

Further focus groups were conducted to test the acceptability of the voucher design and use.

Phase Two

Following Phase One of the project, a further four focus groups were conducted with the target audience and with pharmacists and other health professionals, to assist the development of Phase Two.

Postcode data identifying the location and numbers of the primary audience in Newcastle and Gateshead was provided to the project team. The target population was then mapped and linked to dental practices in each locality, which allowed specific areas to be targeted.



Stakeholder engagement

Securing strategic and professional support for the project would be essential for its later implementation. For this reason, senior health service personnel and key leads in Gateshead and Newcastle Primary Care Trusts (PCTs) were informed and had the opportunity to comment and influence the developed proposals. The project received support from the local oral surgeon's base at Newcastle General Hospital, The Freeman Hospital and Sunderland Teaching Hospital. Attendance at local dental and pharmacy committee meetings and meetings with PCT dental services, smoking cessation services and health development workers gained the support of essential primary care teams, who were included in the planning and made party to the decision-making process.

The exchange

With strategic and professional support, three major strands of the intervention were developed to overcome the barriers identified in the scoping phase:

- Communication to engage with the target population and make self-identification easy
- A user-focused, community-based screening service that was convenient for the target population to use – quick, easy, effortless and painless. This would feature a voucher scheme providing free soft tissue checks, to incentivise users and remove

any perceptions that financial cost were involved

- A special primary care 'sales force' to promote the service to the most at-risk users

By addressing the frustrations of professionals about the existing services (re-designing the screening infrastructure and offering dedicated staff training), Love Your Mouth also benefited health professionals, leading to clinical satisfaction at a good job done and successful engagement with the target audience.

Behavioural theory

The project supported learning from the Health Belief Model (Rosenstock 1974). This model seeks to explain why individuals do or do not carry out certain health-related behaviours, such as attending for cancer screening. It suggests that a person's willingness to change their health behaviour is based on the following factors:

- **Perceived susceptibility** – How likely they think they are to develop a certain condition – unless they believe they are at risk, an individual is unlikely to change their health behaviours
- **Perceived severity** – How serious they think the condition and its consequences are
- **Perceived benefits** – What benefits they see in terms of the positive effects of adopting the behaviour – what's in it for them?
- **Perceived barriers** – How 'hard' they think it will be to change their behaviour and the costs that are involved – money, but also effort, time, inconvenience and disruption to regular routines

Love Your Mouth applied the Health Belief Model by influencing the perceived susceptibility of the at-risk population to the threat of oral cancer, whilst simultaneously promoting the benefits of early detection. In addition, the voucher system and provision of

an easily-accessible screening service within the community acted as a cue to action, minimising perceived barriers to screening and maximising participants' belief in their own ability to attend for cancer screening.

Methods mix (4Ps)

- **Product:** A customer-focused mouth examination service accessible and user-friendly to those at risk from oral cancer
- **Price:** Ease of access for the target population at low or no cost
- **Place:** Delivered at the target population's preferred locations, without compromising on delivery of the correct level of clinical competence
- **Promotion:** Enthuse and skill up health professionals in contact with the target audience, develop a primary care 'sales force' and a communications strategy

Awareness raising

To raise awareness about the symptoms of oral cancer and risk behaviours, non-paid for local media was used (editorials, features and news in print and broadcast media), as well as indirect awareness raising through primary care settings (posters and information sheets).

Numbered voucher system

The voucher system enabled the holder to receive a free soft tissue mouth check at a participating dental practice.

A number of appropriate primary care teams and dental practitioners in Gateshead and Newcastle were identified and recruited into the scheme. Letters of invitation were sent with a brief outline of the project and inviting participation. Subsequently, 2,000 Love Your Mouth vouchers were distributed to pharmacies, smoking cessation services, health trainers, NHS walk-in centres and some medical practices in the Newcastle and Gateshead area (involving approximately 50 per cent of healthcare professionals in each area). These professionals were trained to carry out an opportunistic risk assessment prior

to issuing an individual with a voucher so that only those most at risk were referred through the service.

Once this risk assessment had been completed, an onward referral to a General Dental Practitioner was made and the voucher provided a method of payment for the screening. It also provided a record of every individual involved in the system and their clinical outcome, without revealing their identity to the project team.

Training

Training sessions were provided to primary care workers who agreed to 'risk assess' before offering a voucher and to dental teams. Participating dental practices were offered training in communication involving role play or use of a training DVD.

Information packs were also provided to support the training, which contained:

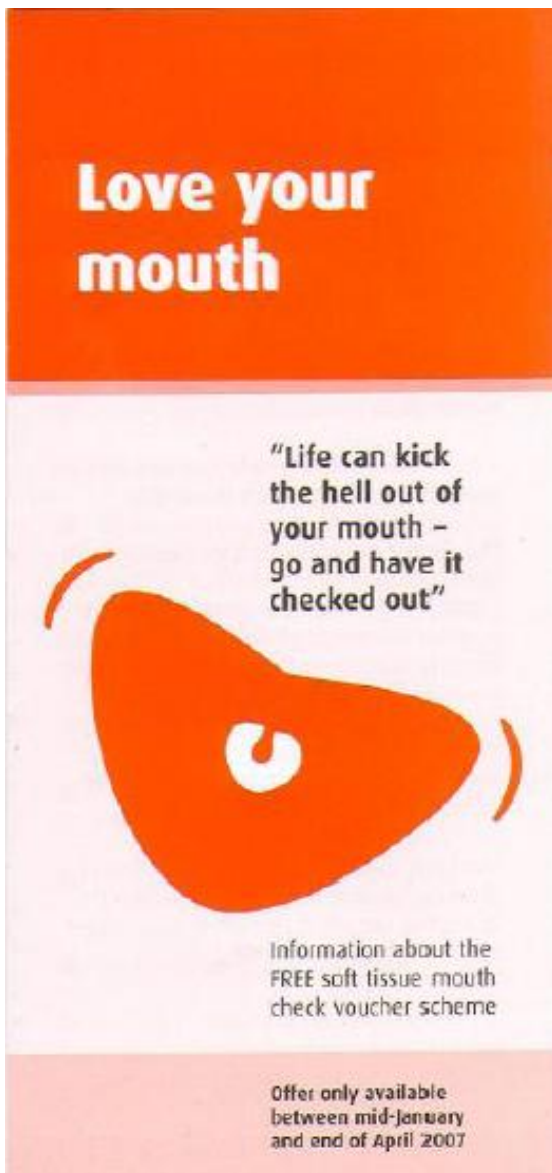
- Team contact details and presentation handout
- List of participating pharmacies and dentists in the Newcastle and Gateshead area
- Summary chart outlining participants' involvement
- Flow chart for the voucher scheme
- Mouth Cancer Referral Guidelines – A pictorial A4 chart appropriate for dentists, medical practitioners and pharmacists (Cancer Research UK)
- Leaflet titled *Open up to mouth cancer – how to detect it early* (Cancer Research UK)
- Research paper titled *Patient's delay in oral cancer: a systematic review* (Scott, S. E., Grunfeld, E. A., and McGurk, M.)

- Love Your Mouth posters

Resources

To facilitate the implementation of the voucher scheme, the following resources were produced:

- 2,000 vouchers, in books of 20, for a free Love Your Mouth soft tissue mouth check
- Voucher information leaflet
- Promotional posters, to be displayed by participating services
- List showing participating dental practices in Newcastle and Gateshead



Participating dental practices were also provided with a record sheet to monitor

contacts presenting Love Your Mouth vouchers (enabling voucher serial numbers to be recorded, along with date of appointment and if the person failed to attend for their appointment), as well as five blank voucher replacements (enabling serial numbers to be added if people attending for booked appointments forgot or no longer had their voucher). This system enabled the project team to effectively evaluate the process – how many vouchers were issued, who accepted a voucher, where and by whom the voucher was issued, who made an appointment, who kept the appointment and who failed to attend.

Phase Two: Recruiters

Phase Two used the same process as Phase One for delivering the intervention, with the addition of enlisted recruiters. These were people with expertise in on-street marketing techniques who worked in targeted localities, approaching members of the public within the relevant age group and, following a brief interview questionnaire, offering a voucher and list of participating dental practices in the area. Recruiters focused on localities known to have a higher percentage of adults with risk factors for mouth cancer to enhance engagement in those areas.

In addition, the images used on the vouchers and other materials were amended for Phase Two after feedback from the target audience following Phase One.



The Love Your Mouth voucher scheme was launched to the media on 16 January 2007 with a photograph and interview opportunity held at Newcastle PCT Dental Services. The event included local Newcastle United football legends with links to mouth cancer and a local dental practitioner who had suffered from

mouth cancer. This was covered by local television news programmes, radio stations and articles printed in local newspapers the following week. The launch was also supported by representation from the DH and Cancer Research UK. A further awareness raising opportunity took place at Blaydon Shopping Precinct, Gateshead on 5 February 2007, using the BBC Blue Bus live radio programme.

Phase Two was launched in August 2008 and ran until January 2009. A key success of Phase Two was the research to identify the location and numbers of the target audience, which enabled the project team to assess the impact the project was having on this hard-to-reach group.

“The most successful thing was that we used new techniques to find the target audience. Often people find it hard to identify the target audience, where they are, how many of them there are. I think we did that well, we knew precisely where our target audience were, we knew by the end how many there were and what our reach was, and we knew precisely how many we’d got in and in what way. The voucher system and tracking was probably the most successful thing we did.” (Dr Ray Lowry, University of Newcastle)



In an attempt to increase uptake of the voucher scheme in Phase Two, the project added on-

street recruiters to target key areas and recruit appropriate members of the public. Unfortunately, this did not turn out to have the desired impact. While they approached and issued vouchers to a large number of people, there was a very low rate for these vouchers being exchanged for a soft mouth check.

“The least successful aspect was the on-street recruitment to try and find the target audience. We didn’t get as many respondents as we wanted to, but until you try you don’t know.” (Dr Ray Lowry, University of Newcastle)



Vouchers allowed clear tracking and evaluation of project participation. The voucher recipient presented the voucher to the participating dentist at the time of the appointment, enabling the examining dentist to complete the back of the voucher with the patient’s age, gender, postcode and details of the soft tissue check outcome (failed to attend, referred, advised routine care, accepted for routine care).

The voucher was then collected by the project team at the end of the project phases and matched with the stub, to facilitate evaluation. This system enabled the team to effectively evaluate the process – how many vouchers were issued, who accepted a voucher, where and by whom the voucher was issued, who made an appointment, who kept the appointment and who failed to attend.

Phase One

Quantitative results

- Between 30 and 40 per cent of dentists and pharmacists in Newcastle and Gateshead were involved during the 4-month pilot

- 1,584 Love Your Mouth vouchers were distributed – however, of these 1,131 (71.4 per cent) were not issued by distributors
- 205 initial ‘assessment of risk’ vouchers were given out by distributors (12.9 per cent of the total distributed)
- Of these, 50 (approximately 24 per cent) then went on to make and attend dental appointments for a soft tissue mouth check
- Participating dentists providing the soft tissue mouth checks referred 5 voucher holders (10 per cent) on to specialist oral surgeons using the existing common pathway
- Of these, one person was kept under review

Qualitative results

Focus groups were conducted to evaluate the communications strategy and the customer focus of the screening and referral system, which informed the development of Phase Two of the project:

- Half of the participants were aware of the campaign
- The Love Your Mouth slogan, logo and the colour of the logo was well recalled, although the logo needed to look more like a mouth
- The campaign was perceived as being not shocking enough to grab attention
- People wanted facts and figures on cases of oral cancer, bold wording and clear communication
- The communications needed to further highlight that the soft tissue mouth check was free
- Laziness, no free time, lack of trust in dentists and fear of finding something wrong were the key barriers to making an appointment

Questionnaires were given to all participating primary care teams. Responses from distributors identified that while initial training was well received, updates throughout the project would have been beneficial. Distribution of vouchers was not always seen as a priority.

It can be inferred that primary care teams were not proactive in identifying at-risk customers, because they felt a lack of engagement in the project. Subsequently, further work needed to be conducted to identify the issues that resulted in 71 per cent of vouchers not being issued by distributors.

Phase Two

Quantitative results

- Slight increase in the number of healthcare professionals responding to the letter inviting them to participate in Phase Two – many had previously supported the intervention
- 1,000 Love Your Mouth vouchers were distributed, and of these 492 (49.2 per cent) were not issued by distributors, down from 71.4 per cent during Phase One
- 280 initial ‘assessment of risk’ vouchers were given out by distributors (28 per cent of the total distributed), up from 12.9 per cent during Phase One
- Of these, 51 (18.2 per cent) went on to make and attend dental appointments for a soft tissue mouth check, down from 24 per cent during Phase One



Since completion of the project, Cancer Research UK is considering the possibility of directly managing and/or operating the soft tissue mouth check voucher system in the future. The following options have been identified for taking the work further.

At a local level

- The voucher system could be used for specific campaigns linked to mouth cancer awareness week
- Risk assessment and vouchers could be made available through existing local patient services, such as Patient Advice and Liaison Services

At a national level

- Medical practitioners and pharmacists could print computer generated vouchers redeemable at any dental practice
- Vouchers could be printable following an online self risk assessment from the Cancer Research UK website
- Vouchers could be requested through a free national helpline number

Results and learning from the project have been shared widely, including on the Cancer Research UK website and in published articles in journals such as the Social Marketing Quarterly.

Lessons learned

This intervention was successful in as far as a new system was developed that engaged with a target population at risk from oral cancer and drew them into a clinical screening service.

Targeting at-risk audiences

Using sophisticated mapping techniques meant the project was able to estimate the total population at risk, show the high rate of reach for the intervention, and the proportion of the at-risk population using the service – something many projects struggle to achieve.

Engaging primary care (the ‘sales force’)

Phase One of the intervention highlighted the importance of not only engaging the target audience, but also primary care as key stakeholders, to encourage them to distribute the vouchers. Primary care staff needed to feel more engaged with the project and be updated regularly on the project’s progress.

“When you decide what the focus of the work is, you can very quickly decide who the key players are. It takes two to tango – you have your target audience, and they usually or potential interact with someone quite closely, in this case primary care.” (Dr Ray Lowry, University of Newcastle)

Voucher system

The voucher system worked. It provided a simple monitoring and evaluation process, it maintained recipient confidentiality and it was accepted by those involved. The delivery mechanism, however, needs more consideration because incentives to pharmacists and medical practitioners, and the use of recruiters did not fully remedy the problem of low levels of distribution of the vouchers.